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Representative Ryan I. Yamane, Chair Representative Dee Morikawa, Vice Chair HOUSE COMMITTEE ON HEALTH

March 20, 2012 – 9:00 a.m. State Capitol, Conference Room 329

Regarding S.B. 3039, SD1 Relating to Anatomical Transplants

Chair Yamane, Vice-Chair Morikawa, and Members of the Committee:

My name is Karen Schultz, RN, MS, Vice President, Patient Care /Behavioral Health Services, Surgical Services, Orthopedics and Transplant. I am the current executive overseeing the new transplant program at the Queen's Medical Center (QMC). QMC is providing comments on SCR58, Requesting Health Care Facilities and Health Care Providers in Hawaii to Perform Organ Transplantation on Patients with HIV, ARC, and AIDS. We respectfully suggest that the resolution is unnecessary.

Patient selection criteria for an organ transplant are highly individualized based on the best possible outcome. Transplant programs are heavily regulated by Federal agencies. As a new transplant program, our outcomes will be monitored closely by Centers of Medicare & Medicaid (CMS) and United Network of Organ Sharing (UNOS) Organ Procurement and Transplantation Network (OPTN). Patient selection for medical diagnosis follows UNOs/OPTN and CMS best practices guidelines.

Thank you for this opportunity to provide comments on this measure.



Committee:

Committee on Health

Hearing Date/Time:

Tuesday, March 20, 2012, 9:00 a.m.

Place:

Room 329

Re:

Testimony of the ACLU of Hawaii in Support of S.B. 3039, SD1

Dear Chair Yamane and Members of the Committee on Health:

The American Civil Liberties Union of Hawaii ("ACLU of Hawaii") writes in support of S.B. 3039, SD1.

Health care providers should not be able to use religion to discriminate against patients who do not share their beliefs by denying them adequate medical care. Although HIV may no longer be a death sentence, a health care provider's refusal to provide an organ transplant might be. This just and compassionate bill will save lives and end what may be the most egregious example of discrimination against those living with HIV.

The mission of the ACLU of Hawaii is to protect the fundamental freedoms enshrined in the U.S. and State Constitutions. The ACLU of Hawaii fulfills this through legislative, litigation, and public education programs statewide. The ACLU of Hawaii is a non-partisan and private non-profit organization that provides its services at no cost to the public and does not accept government funds. The ACLU of Hawaii has been serving Hawaii for over 40 years.

Thank you for this opportunity to testify.

Sincerely,

Laurie A. Temple Staff Attorney ACLU of Hawaii

Committee on Health

Representative Ryan Yamane, Chair

Representative Dee Morikawa, Vice Chair

Bill No: SB 3039 SD1

Place: State Capitol Room 329

Date and Time: Monday March 20, 2012 @ 9:00 AM

Testimony in Strong Support!

Testifier: Sol Rattner

On Behalf of: Myself

Aloha Representative Ryan Yamane, Chair Representative Dee Morikawa, V. Chair and Committee Members,

Thank you for allowing me to testify on this important Bill. I am a former dialysis patient as well as a Kidney Transplant Recipient. I was blessed with the Gift of Life, here on Oahu, on March 24, 2004.

People try to dictate to others how to live their lives and under a decree that they can or cannot get medical help. The HIV+ patient does not qualify for transplants because of their medical condition. Who dictates these orders? Some are medical professionals and facilities or People in high places, such as The Department Of Health or some Religious Not for Profit?

What makes one person's life who is HIV-, more important than a HIV+ patient does? When having no representation to the process of allowing a now routine transplant procedure to occur and being turned away even though all of their medical physicians recommend surgery is nothing short of prejudice. We are

a wonderful and compassionate State, yet we have never ever had a transplant preformed in the State of Hawaii for any HIV+ patient.

There are transplants being done for HIV+ Recipient patients in 21 States for the past 16 years with a recovery rate greater than the normal HIV- Recipient patients are. Hawaii forces HIV patients to go to the mainland to receive life saving transplants. This Bill would stop the unethical practice of forcing patients to spend a fortune in travel and lodging expenses including hotels & Food, to acquire the Vital Organs they need to live.

Mahalo and Aloha,

Sol Rattner

91-211 Maka'ina Plave

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Committee on Health

Representative Ryan Yamane, Chair

Representative Dee Morikawa, Vice Chair

Bill No: SB 3039 SD1

Place: State Capitol Room 329

Date and Time: Monday March 20, 2012 @ 9:00 AM

Testimony in Strong Support!

Testifier: Lila G. Rattner

On Behalf of: Myself

Aloha Representative Ryan Yamane, Chair Representative Dee Morikawa, V. Chair and Committee Members,

Thank you for allowing me to testify. Having a husband who received a Kidney Transplant in 2004, I am aware of the procedures required to obtain one. I realize that the process can be complicated however the facts are that HIV+ patients have been turned down for transplants ever since transplants were first done in Hawai'i. The transplant teams have ignored HIV+ patients because of misinformation and have sent them away to the mainland instead of doing their ethical obligation and transplanting them when necessary.

Lives are being lost, and suffering continues for the HIV+ patient. It is wrong to choose who will live and who will die. Only the Lord has that right.

Medical Facilities on the mainland have been doing surgery on HIV patients for 16 years quite successfully. Patients have a higher rate of recovery than non-HIV patients do. Twenty One Hospitals report of their success.

Please adopt this Bill and put an end to this obvious prejudicial attitude and let start saving lives by having the first ever transplants for HIV patients in Hawaii.

Aloha and Mahalo

Lila G. Rattner

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Committee on Health

Representative Ryan Yamane, Chair

Representative Dee Morikawa, Vice Chair

Bill No: SB 3039 SD1

Place: State Capitol Room 329

Date and Time: Monday March 20, 2012 @ 9:00 AM

Testimony in Strong Support!

Testifier: Joseph B. Rattner O.D., MPH, Csac

On Behalf of: **Myself (as an Individual)

**Founder & CEO: West O`ahu Hope For A Cure Foundation, Inc.

(as an Agency/Organization, Representing the HIV+ Populations of Waianae, Maile, Makaha, Nanakuli, Kapolei, Ewa Beach, Waipahu, Aiea, Pearl City, Wahiawa and parts of the North Shore e.g. Laie, Waialua)

Aloha Representative Ryan Yamane, Chair Representative Dee Morikawa, V. Chair and Committee Members,

Mahalo nui loa, Chair Yamane, for stepping up to the plate and calling this time sensitive Hearing!

When I moved to O'ahu from the Metropolitan Area of New Jersey and New York 10 yrs ago, never in my wildest imagination, would I believe the excuses for Stigma and reasoning for Discrimination, coming from Professionals and Religious Not for Profits, creating a defined destiny for all HIV+ Patients in need of an Organ Donor Transplant in Hawai'i.

In early 1986, when I was barely just 19 yrs old, I was diagnosed HIV+, anonymously, by a Conservative Physician, who's main worry, was that her dosing of the only Medication at the time, AZT, would be enough to stop the viruses wrath and not be too much, that it make me so sick, that my body would just give out from the amount of poison levels in my Blood, making me septic anyway and in essence doomed for death!

Luckily, Dr. Cecelia Cetia, the Physician that diagnosed me 27 yrs ago, last Thursday, March 15, 2012, realized before anyone that I had the HIV 1 RNA Virus, but what made my virus different from most Hivers' was that my virus was categorized as a 'Wild Type' Strain, which from the start, was the beginning of a well lived life so far, as an HIV+ Individual, because as a Wild Type Strain, my body would not become resistant for long if ever from all the Medications' in every category, from NNRTIs' (Non-Nucleoside Reverse-Transcriptase Inhibitor) to PIs' (Protease Inhibitors).

As soon as each new Medication, of each new Class (of which there are 4), was made available, my Physicians from back East to here on O'ahu, which after having a few disasters with over prescribing and incorrectly prescribing Docs on the island of O'ahu that almost put me in box for good, led me to see the best Infectious Disease Physician that Hawai'i has to offer, Dr. Willis J.K.W. Chang, out of Pali Momi and Queens, with his Main Office in Waipahu.

When I moved here in August of 2002, I was already on a Regimen which included a Medication that in late October of 2009, the FDA Re-Labeled. The Medication, also used for Hepatitis B & C, is called Viread, and the new Labeling by the FDA, warns that use of this Medication for more than 3 consecutive yrs, WILL CAUSE CKD (Chronic Kidney Disease) and/or KIDNEY FAILURE. Mind you, I had been taking lab work at least every 3 months and there was not one indicative sign that this was coming, no increase of my BUN or Creatinine, and although I was becoming fatigued often, we related this relatively common HIV+symptom to just that, the Virus taking its course.

Well, not even 2 months after the warning label was published by the FDA, wouldn't you know that this predominantly Healthy HIV+ Individual for 24 yrs,

was now not only facing Dialysis, but I was facing it with absolutely no Hope of a Transplant by the past Institute of HMC and St. Francis due to Religious reasons and lack of experience or education.

The intent of this Legislation is to prevent Queen's Medical Center, who graciously stepped up to the plate, post the abrupt closing of HMC East, along with the destruction of 400 HIV- Patients Hope, from denying a HIV+ Individual from becoming a Transplantation Recipient based solely on the fact that they are diagnosed HIV+. Miraculously, Queen's new Transplant Center have already been approved for Liver Transplants and performed their 1st two cases last week, successfully, with Kidney Transplants to be approved in just a few short weeks with Pancreas and Heart Transplants to follow. The blatant Discriminations' and Stigmas', emulated by the Transplant Institute's Team, should hopefully no longer play any sort of role, in the decision of a case for Transplantation, for any Transplantation for a HIV+ Recipient individual whether from a Live or Cadaver Donor!

Presently, Karen Shultz, Vice President of Transplant Patient Care for Queen's Transplant Center stated a month ago during the Senate Health Committee Hearing that Queen's does not discriminate, dependent on Medical Diagnoses, rather, they judge and weigh the possibility of what will be the better outcomes, for the Patient. When I spoke with the Director of the Queen's Transplant Center last week, Lorraine Flemming APRN, she stated her concern of their Center not being sophisticated enough to provide for HIV+ Recipients.

This reasoning reminds me of what Kathy Bailey, my father's Transplant Coordinator when the Institute was in St. Francis East, told me after I was rudely denied without reasoning in black and white, said that the Team just doesn't have the 'experience', when it comes to the aftercare, since the Surgery Procedures are identical. Honestly now, with Webinars being the Education module of the World, I find NO excuse why these Physicians on the Team, can't take the initiative and become the kind of Physicians that Hawai'i can be proud of, by making our Transplant Center the 22nd Center in the Nation, as the ONLY TANSPLANT CENTER in the Pacific, including then Patients from Guam, Samoa, Tahiti and more, to

perform Transplants for the 10% of the HIV+ population in our State and the Pacific in need of a Life Saving Organ. This act is true "kokua", when 75-100 more Transplants save 75-100 or so Patients, with their HIV under control, making them a viable and relatively successful candidate, for the Organ Transplantation they might so desperately need. The statistic below should make your vote today very easy, so if you should need the statistic in black and white, please let me know and I will get it from the UCSF Web site before the Hearing tomorrow morning. Alternately, Senator Joshua Green, M.D., has the hard copy that I left with him shoeing stats for both the Living and Cadaver Donor Programs.

FYI, HIV+ Recipients has been an approved and routine procedure, watched closely by UNOS and OPTN, the National regulatory Agencies for Procurements of Organs and the Network that holds the Registry of all Patients in need of every Organ that can be transplanted. Speaking to my comment that your vote will be made easy, was because the statistic of a cumulative record, of <u>ALL</u> Patients in the Nation that were Blessed with "The Gift of Life" and are HIV+, whether or not the Organ came from a cadaver or live donor, post 5 yrs or more since their Transplant, whether determining the *Health of the new Organ* or the *Health overall of the Patient*, is miraculously 8-12% BETTER, when the Transplantation is from a HIV- Patient to a HIV+ Recipient.

Mahalo nui loa to you all, for giving me the opportunity to Testify on a Timely Sensitive Measure, which when amending the Draft to be effective upon approval, and not in 2050, when most are in need now and not in 20 yrs none the less almost 40 yrs, as most would probably be dead by the time HI mandated this new Statute!

Medical Equality for All, should be a G-d given right and not determined by a Human, that uses reasons such as being HIV+, as an excuse not to let that person live longer and longer, to one day die by natural causes. Ladies and Gentlemen, as a Long Term Survivor, I employ you to PASSS this Measure out to the Judicial Committee and change the defective date to be approved upon approval, since a Conference Committee is eminent.

Malama Pono and Aloha,

Joseph B. Rattner O.D., MPH, Csac

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morikawa2 - Grant

From:

mailinglist@capitol.hawaii.gov

Sent:

Monday, March 19, 2012 11:59 AM

To:

HLTtestimony

Cc:

HIITSMARTÁ@AOL.COM

Subject:

Testimony for SB3039 on 3/20/2012 9:00:00 AM

Testimony for HLT 3/20/2012 9:00:00 AM SB3039

Conference room: 329

Testifier position: Support Testifier will be present: No Submitted by: MARTA ZAMORA Organization: Individual E-mail: <u>HIITSMARTA@AOL.COM</u> Submitted on: 3/19/2012

Comments:

morikawa2 - Grant

From: Sent:

Marie T [mariet808@yahoo.com] Sunday, March 18, 2012 12:15 AM

To: Subject: HLTtestimony testimony

March 17, 2012

To whom it may concern,

My purpose for this petition is to recognize the state Bill S33039SDI that prohibits discrimination against a person who has human immunodeficiency virus (HIV), acquired immune deficiency syndrome (AIDS), or AIDS-related complex (ARC), from receiving organ transplantation.

As a hemodialysis technician, I know first hand the perseverance consumers have to keep their life going despite other health issues. Regardless if a person has HIV, AIDS, or ARC, they should not be refused a transplant if they are in compliance of keeping themselves healthy and strong. Everyone deserves a second chance!

Thank you for your time, Maryline Tagama